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ABSTRACT

A survey of families of 54 children or adolescents with deaf-blindness examined parents' beliefs regarding issues of friendship for their children. The mean age of the children was 11.4 years. Approximately 65 percent of the children attended a special school and 35 percent attended a program within a regular school. Almost 75 percent were identified as having another disability such as mental retardation or physical disability. Parents were asked for their agreement/disagreement with 50 statements grouped within seven categories: (1) communication and sensory impairments; (2) independence and mobility; (3) community issues and concerns; (4) integrated versus self-contained programs; (5) similarities of friendship; (6) social network; and (7) having friends with disabilities. Preliminary results indicated that parents of children with deaf-blindness are concerned about issues of friendship. Parents were most concerned with the child's social network, communication and sensory abilities, and community issues. Other findings included: 74 percent of parents felt their child had fewer friends due to his/her deaf-blindness; 81 percent believed that moving to a new community would be harder for their family than other families; and 70 percent did not think their child would prefer as a best friend another person who is deaf-blind. (DB)

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ED 461 186

Friendships of Children with Deaf-Blindness: Parent Perspectives and Experiences

Nancy Sall, M.S.
Annual TASH Conference in San Francisco, December 1, 1995

The Social Relationships of Children and Adolescents with Deaf-Blindness research project based at the Developmental Disabilities Center of St. Luke's/Roosevelt Hospital in New York has been involved in several different research activities over the past three years. Most recently, the project has completed a survey on parent perspectives of friendship. The purpose of the survey was to gain insight into parents' beliefs regarding issues of friendship for their children with deaf-blindness.

Method and Procedures

The survey was designed as a questionnaire which could be administered either through an individual interview or through the mail. This method was selected because the nature of the study required a flexible approach which could include parent respondents who did not live in the metropolitan area and who were not able to come in to the hospital for an individual interview.

Participants

Fifty-four families throughout New York State were involved in the survey. Criteria for participating in the study was based on the child's disability, such that the child had concomitant hearing and vision impairments and was within the ages of 3 to 23 years. Families participating in the study represented a diverse range of ethnic, racial, socioeconomic, and religious backgrounds. Parents were identified through various procedures. The majority of parents were known to the researchers through an on-going study on social relationships of children with deaf-blindness. Parents were also contacted through an advocacy organization working with families of children who are deaf-blind, and some of the families were contacted directly through their child's school.

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The mean age of the children whose parents participated in the study was 11.4 years. Approximately 65% of the children attended a specialized school program (residential, special school, or home school) and 35% attended a program within a regular school (special education class or general education class). Thirty-three percent of the children were identified as having a mild or moderate hearing loss; forty-three percent were identified as having a severe or profound loss; and, twenty-three percent were not identified as having a specific loss or their parents did not know the degree of hearing loss. Thirty-seven percent of the children were known to be totally blind or to have only light perception; fifty-nine percent were identified as being partially sighted or legally blind; and, four percent of the parents responding did not know the degree of their child's vision loss. Almost 75% of the children were identified as having another disability, such as mental retardation or physical disability.

Data Collection and Analysis

Parents participated in the survey either by coming to the hospital center for an individual interview with a member of the research staff or by completing a mailed questionnaire. A staff member from the research project initially contacted parents through a letter describing the purpose of the study, which also included informed consent. If the parent expressed an interest in participating in the survey, an appointment was scheduled to take place at the hospital center. Each interview lasted approximately 60 minutes. For parents living outside the metropolitan area, a questionnaire was mailed with a postage-paid return envelope. These parents were asked to complete the questionnaire and return it to the research staff. The questionnaire, including a section on demographic data, took parents about 20 minutes to complete.

The questionnaire was constructed with 50 closed-ended questions. Respondents were asked whether they strongly agreed, agreed, disagreed, or strongly disagreed to each item. The fifty items in the questionnaire were grouped within seven categories, or indexes. The indexes included: (1) Communication and Sensory Impairment; (2)

Independence and Mobility; (3) Community Issues and Concerns; (4) Integrated Versus Self-Contained Programs; (5) Similarities of Friendship; (6) Social Network; and, (7) Having Friends with Disabilities. These indexes were used to compile scores from all of the 50 questions and to identify one composite score per category. Each index consisted of 5 to 9 questionnaire items.

Results

Preliminary results from the survey are presented as composite scores within each of the seven indexes as seen in Figure 1 (see the last page). Listed below are examples of questions that parents responded to, followed by the general responses with percentage of agreement or disagreement that parents assigned to the particular item. Where do you stand on these issues?

- Do parents think their child has fewer friends because he or she is deaf-blind?
(74% do)

- Do parents feel other children would play more with their child if they knew more about deaf-blindness?
(74% do)

- Do parents believe their child's limitations in mobility prevents them from going hiking with other children?
(69% do)

- Do parents feel it would be impossible for their child to play basketball with neighborhood children?
(59% do)

- Do parents believe that moving to a new community is harder for families who have a deaf-blind child than for other families?
(81% do)

- Do parents think their child would do better if he or she were in a regular class and not a special class?
(66% do not)

- Do parents feel a regular class placement would help their child make friends more easily?
(68% do not)

- Do parents believe that hobbies, such as collecting baseball cards, playing an instrument, or painting, are meaningful for their child?
(56% do)

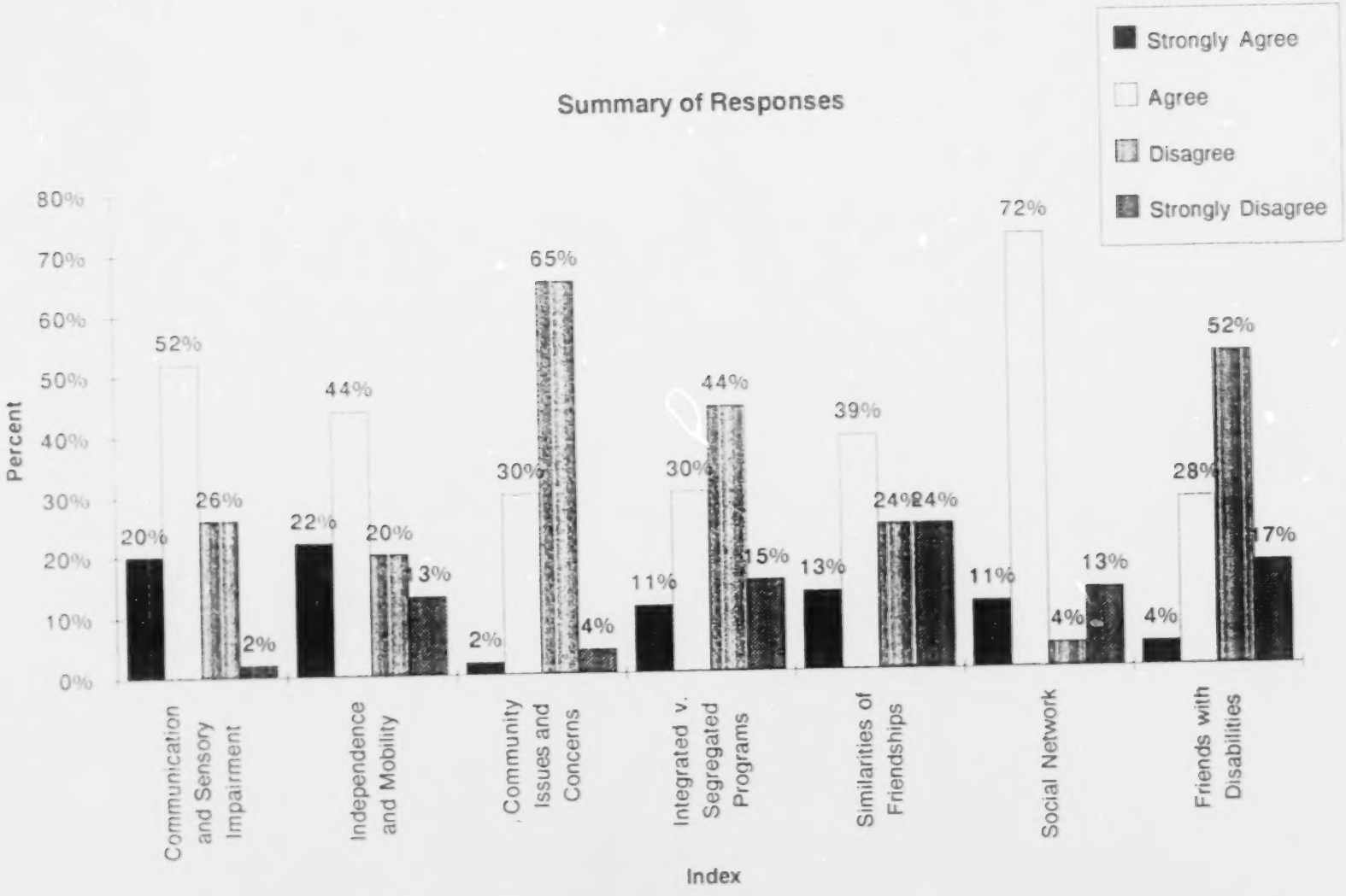
- Do parents feel that neighborhood children are likely to play with each other more than with their child?
(85% do)

- Do parents think their child would prefer as a best friend another person who is deaf-blind?
(70% do not)

Discussion

The preliminary results of this survey indicate that parents of children with deaf-blindness are concerned about issues of friendship. While all components of friendship are important to consider, this survey has revealed that certain factors more clearly impact upon the development and maintenance of friendship than others. A child's social network, communication and sensory abilities, and the community's awareness and availability have been identified by parents as those categories of friendship with which they are most concerned and/or most affect their child's development of friendships and social relationships.

Further data analysis is needed, and is currently being conducted, to more specifically look at the different factors affecting friendships as well as to identify what their relationship is between age, degree of disability, and school setting on the development of friendships.


Summary of Responses
Strongly Agree
Agree
Disagree
Strongly Disagree
Percent
80%
70%
60%
50%
40%
30%
20%
10%
0%
20%
52%
26%
2%
22%
44%
20%
3%
2%
30%
65%
4%
11%
30%
44%
15%
13%
39%
24%
24%
11%
72%
4%
13%
4%
28%
52%
17%
Communication and Sensory Impairment
Independence and Mobility
Community Issues and Concerns
Integrated v. Segregated Programs
Similarities of Friendships
Social Network
Friends with Disabilities
Index